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EFFECT OF METHOD OF TREATMENT ON HEALTH RELATED QUALITY OF LIFE AMONG JORDANIAN CHILDREN AND ADOLESCENTS WITH CONGENITAL HEART DEFECTS

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ABSTRACT

Congenital Heart Defects (CHD) are structural defects of the heart which are present at birth, even if it is not discovered at that time [1]. CHD are the most common congenital anomalies in the world, accounted for one-third of the major birth anomalies [2]. The American Heart Association (AHA) reported in their statistical fact sheet in 2012 that the reported incidence of CHD in the United States of America was from 4 to 10 per 1000 live births [3], and according to the Centers

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INTRODUCTION

Back Ground

Increased survival rates among children and adolescents with CHD through childhood and adolescent have an influence on their well-being, as it is involved with reduced physical, social or psychological functioning [5, 6]. As a consequence, it will affect different outcomes of health, as Health-Related Quality of Life (HRQoL) [7]. Moreover, the influence of CHD in children and adolescents is increasingly being a concern to be investigated among this age group due to its long-term consequences; hence, the identified risk groups with decreased level of Quality of Life (QoL) and HRQoL may benefit from programs directed towards the improvement of children's conditions [8]. Health-related quality of life was defined as an individual, multidimensional construct, denoting to the measure of quality of life which is concomitant with health, and addresses personal awareness of physical, emotional, and social functioning and well-being [9].

For proper evaluation of the HRQoL, it is important to address several factors that affect the HRQoL in children and adolescents with CHD. Nevertheless, studies show contradictory results due to many factors, such as the demographic variables of the children and adolescents, severity of the heart defect, approaches to the treatment either conventional medical treatment or different approaches of surgical correction interventions [10–12].

It is important to evaluate the level of HRQoL among the children and adolescence with CHD after surgical corrective procedures as a routine assessment post operatively, as the assessment that is done usually evaluates how much the signs and symptoms of congenital defects were relieved. However, this routine assessment may not thoroughly evaluate the burden that occurred on the patients due to the complex treatment, the physical limitations, and the perception of children and adolescents of adjustment and adaptation after the cardiac surgery [13].

The advancement in the diagnostic methodologies in pediatric cardiology, and therapeutic medical and surgical procedures decreased the death rates significantly and enabled those children and adolescents to survive through infancy to older developmental stages of childhood and adolescence [11; 8].As a construct, HRQoL indicates the subjective perception of individuals of the influence of their illness and treatment on their reported level of life quality [11]. The construct of HRQoL had been used as a measurement of health outcome due to the physical, emotional and functional consequences of CHD in children and adolescents through their life [11;14;15].

Tahirovi and colleagues [16] studied the QoL in children after cardiac surgery, the authors utilized PedsQL™ 4.0 Generic Core Scales self-reports and parents proxy-reports to evaluate the QoL for children from the age of 2 to 18 years-old and compared their results to normal children. The overall QoL was significantly lower than healthy peers. However, children aged from 13 to 18 reported significant lower QoL than their parents' proxy reports. As for parents proxy reports, scores were lower in overall QoL after cardiac surgery for all other age groups from 2 to 12 years-old. Moreover, School functioning scale scores were lower in children aged from 5 to 7 and adolescents aged 13 to 18 [16].

Other studies had evaluated the level of QoL for children and adolescents with different diagnoses of CHD, taking into consideration the surgical approach to correct the congenital defect which makes it difficult to draw conclusions from those studies. Gaies and colleagues [12] had evaluated the QoL of children and adolescents after surgical correction of transposition of the great vessels using self-reports and parents' proxy-reports of the PedsQL™ 3.0 Cardiac Module and compared the results with cohort group of healthy children. The results showed similar scores between parents' proxy reports of the anatomic repair group and the non-anatomic repair group on all domains of HRQoL. Moreover, the group of children and adolescents who underwent anatomic repair of the transposition of the great vessels only reported significant lower scores on the school functioning subscale when compared to the group who had non-anatomic repair of the defect [12]. The fact of having different subtypes and classifications of CHD that needs different surgical interventions in different stages of life produce different results of the influence of the CHD on the reported level of HRQoL.

Aim

The aim of this study is to answer the research question: Is there a difference between medically and surgically treated CHD, and the level of HRQoL among children and adolescents?

METHODS

Measures

The demographic data questionnaire was filled by the researcher. The data about the following demographic variables were obtained from both the participants and their parents themselves; age, school grade, age at diagnosis, type of medical insurance, history of admission to the hospital, surgical history, income level, and educational status of the parents.

The data for the other demographic variables were taken from the participants' medical file. To have an access to the medical file, a user name and password were obtained from the Electronic Health Solutions Company that runs HAKEEM electronic file software at the JRM. The diagnosis, method of treatment, frequency of admissions, last date of admission, date of last surgery were obtained from the medical file.

The PedsQLTM is a group of measures that depend on a modular system that measures HRQoL in pediatrics from different age groups in which each age group has a specific measurement that would take into consideration the cognitive and physical development differences for each age group. This model, which was developed by Professor James Varni is used to assess the HRQoL in children and adolescents who are healthy and those who had an acute or chronic health condition [17].The Child and Parent Reports of the PedsQL.TM 3.0 Cardiac Module for Children (ages 8–12), and adolescents (ages 13–18) is composed of 27 items comprising six dimensions related to Heart Problems and Treatment (7 items). The Treatment II (5 items), perceived physical appearance (3 items), treatment anxiety (4 items),cognitive problems (5 items), and communication (3 items) for child self-report ages 8–18 years and parent proxy report in all age groups. Parent proxy-reports concerned with parent's perception of their child's HRQOL. The items for each of the forms are basically identical, but the language differs in developmentally appropriate wording and the use of the first or third person for child self-report or parent proxy-report, respectively. The instructions for scoring the PedsQL. TM 3.0 Cardiac Module ask how much of a problem indicated in each item has been identified during the past month. A 5-point Likert scale is used across child self-report for ages 8–18 years and parent proxy report from 0 = never a problem to 4 = almost always a problem). Each item is then reverse-scored and linearly transformed into a 0–100 scale so that high scores indicate a better HRQoL. The items are reverse-scored and linearly transformed to a scale from zero to 100 points (0=100, 1=75, 2=50, 3=25, and 4=0). To create scale scores, the mean is computed as a sum of the items over the number of items answered (this includes missing data). If more than 50% of the items in the scale were missing, the Scale Score is not computed. Imputing the mean of the completed items on a scale when 50% or more are completed is generally the most unbiased and precise method.

Procedure

Participants and Settings

A non-probability convenient sampling design was used, through which all individuals in the accessible population were invited to participate in the study and met the inclusion criteria for a specified sample size; and therefore, reduced the risk for bias [18]. The sample size was 227 pairs of children and adolescents and one of their parents (454 participants). Only one parent had the questionnaire to fill them and didn't return it back. The total response rate was 99% as the questionnaires were filled by the participants in the presence of the researcher who checked each one for missing data before the participants leave.

Inclusion Criteria were Jordanian children and adolescents with congenital heart defects defined by Mitchell et al. [19] as "Structural abnormalities of the heart and/or great intrathoracic vessels that are actually or potentially of functional significance". Participants and their parents who had a history of surgically treated CHD, and non-surgically treated heart defects using medical treatment, or corrected with interventional cardiac catheterization techniques. Age greater than or equal to 8 years for children, and less than 18 years for adolescents, who were able to read and write, and whose parents signed a written consent were included in the study. Exclusion criteria: Participants were excluded if they had cognitive, neurological, and/or physical limitations that inhibited them to fill out questionnaires; who had acquired heart problems such as rheumatic heart disease or electrophysiological problems that are not related to CHD; and participants and/or their parents who did not consent to participate.

Settings

This study was conducted in Queen Alia Heart Institute (QAHI) at King Hussein Medical Center (KHMC). Queen Alia Heart Institute is a specialized center for cardiovascular diseases which has 176 total beds number, and it has pediatric cardiology specialty clinics and units where the target sample was approached.

Ethical Considerations

Several steps were carried out to guarantee the protection of the participants' rights. The approval from the IRB of the Royal Medical Services (RMS) was obtained prior conducting this study. The purpose of the study and data collection process was explained to the nursing director, Head Chief of the Pediatric Cardiology and Head Chief of the Pediatric Cardiac Surgery Departments in QAHI to facilitate data collection. This study was performed in accordance with ethical standards, as described in the Belmont Report which articulated three essential ethical principles that form the basis for standards of the ethical conduct in research. Those primary principles are beneficence, respect for human dignity, and justice [20]. The right to privacy was protected by ensuring the participant confidentiality through taking several steps. Identification code number was used and placed on each questionnaire package. All related data that identify the participants were kept in a locked cabinet in a secured location. Only the researchers had an access to the data collected only for the research purpose. Parents were asked to sign an informed consent form after explaining the purpose of the study, and an assent was obtained from the children and adolescents as a gesture of respect for their autonomy.

Data Collection

Data collection was conducted using self-reported questionnaires at QAHI. The eligible participants were recruited while they were waiting for their scheduled appointment at the out patients' pediatric cardiology and cardiac surgical clinics at QAHI. The participants and their parents were approached at the waiting area outside the clinics; a brief explanation about the study was given for them to obtain their primary agreement to participate. The participants were given the study questionnaires package and an explanation was given about the questionnaires' items, response options and way of scoring.

RESULTS

Table 1: Demographic Characteristics of the Participants (N= 227)

Variable	Mean (SD)	Frequency (%)
Age Children (8-12 years) Adolescents (13-18 years)	12.71 (3.3) 9.9 (±1.8) 15.2 (±3.3)	227 108 (47.6) 119 (52.4)
Gender Female Males		117 (51.5%) 110 (48.5%)
Diagnosis OF CHD VSD PS TGV TOF Dextrocardia AS Tricuspid Atresia	-	59 (26.0%) 30 (13.2%) 31 (13.7%) 47 (20.7%) 14 (6.2%) 15 (6.6%) 1 (0.4%)
Treatment Method Surgical Medical	-	107(47.1%) 120(52.9%)

Table 1 shows the demographic characteristics of the participants, the participants' age ranged from 8 to 18 years-old, mean age of the total participants was 12.71 (SD + 3.332). The results of the socio-demographic characteristics of the participants (N=227) revealed that the entire sample included 117 (51.5 %) female children and adolescents and 110 (48.5 %) male children and adolescents.

An independent *t* test was performed to assess whether mean score of HRQoL differed significantly for a group of 107 children and adolescents who underwent surgical procedure for CHD (group 1) compared with a group of 120 of children and adolescents who had medical treatment for CHD (group 2). Preliminary data screening indicated that the scores on HRQoL are normally distributed. The assumption of homogeneity of variance was assessed by the Levine's test, $F = 2.822$, $p = 0\ .094$; this indicates no violation of the equal variance; therefore the pooled variance version of the *t* test was reported. The mean HRQoL of the surgically treated group differ significantly from the mean score of the medically treated group, $t = 3.822$, $p \leq 0.001$, two-tailed. The mean HRQoL score for the surgically treated group ($M = 52.51$, $SD = \pm 13.38$) was about 6.52 lower than the mean score of HRQoL for the medically treated group ($M = 59.03$, $SD = \pm 12.31$). The 95% CI for the difference between sample means, M_1 - M_2, had a lower bound of -9.880 and an upper bound of -3.158. The effect size, as indexed by partial eta squared (η^2) was calculated ($\eta^2 = 0.507$), this is a large effect size.

DISCUSSIONS

Children and adolescents with CHD may have medical treatment or surgical interventions to correct the congenital defects or to control the symptoms associated with it or may result due to the complications of the hemodynamic disturbances. The participants in this study had reported that the surgical intervention would have a negative influence on their reported level of HRQoL; children and adolescents who underwent surgical treatment reported lower HRQoL (Mean = 52.51) than those who had medical treatment. The result is congruent with results of Tahirovi colleagues [16], who reported that the children and adolescent after surgical correction for CHD had reported significantly lower overall QoL. Moreover, the results are in line with those found by Landolt and colleagues [10], where they found that children who ad surgical corrective procedures reported an overall poorer HRQoL and reported low scores on the physical, social, cognitive and sense of autonomy domains [10]. However, the results contradict the findings of Heusch and colleagues [21] who reported that different surgical techniques didn't affect level of HRQoL to a large extent, yet repeated surgeries lower the reported HRQoL.

The low level of HRQoL among Jordanian children and adolescents who underwent surgical repair may be due to prolonged and recurrent hospitalization, absenteeism from school, physical appearance embarrassment due to surgical scars, and limitations in physical activities which all would affect their social interactions with family and peers. This urges the need for proper comprehensive evaluation and assessment for this age group, to detect those who are at risk for impaired QoL which limits their coping and adaptation, as this was emphasized in the literature [16; 21].

CONCLUSIONS

Jordanian children and adolescents with CHD who were surgically treated reported significant low level of HRQoL in comparison with those who had medical treatment for the CHD.

Declarations

Ethical Approval

This article does not contain any studies with human participants performed by any of the authors.

Competing Interests

Dr. Varni holds the copyright and the trademark for the PedsQL™ and receives financial compensation from theMapi Research Trust, which is a nonprofit research institute that charge distribution fees to for-profit companies that usethe Pediatric Quality of Life Inventory™. The PedsQL™ is available at the PedsQL™ website [20].

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Conflict of Interest: The authors declare that they have no conflict of interest.

Consent Form: A signed informed consent had been obtained from all participants prior to filling the questionnaires.

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